Unidentified Carer of many family members Interviewed May 8, 2019

Carers of people with mental health concerns need to be recognized as a major and irreplaceable part of the overall health care system in Australia. They need recognition and support.

Family carers of mental health patients are not just looking after the patients themselves but are often looking after the patients' children as well. With an increasingly aging population, carers are often looking after multiple generations—possibly a child of their own, that child's children and even perhaps an aging parent with mental health issues as well. The number of Australians looking after relatives with mental health problems has become a major component of the Australian population. I've read reliable estimates of 1 in 5 Australians experience mental health concerns. Think that would mean that there is family and friends around each one of them that care and are concerned for them. So nearly every family would have experience of caring for a loved one with mental health concerns.

Just imagine the cost savings to the government and public expenditure that these family carers are making. They should be given full support if for no other reason that it makes good economic sense.

I am someone who is looking after more than one person. I have been my parents primary carer when first hospitalized in Ballarat with acute schizophrenic disorder. In addition, I have a close family member with acute mental health issues and I have been also been caring for her children as well.

No one actually listens to the carers as to what is going on and this adds to the stress that we are under. We are with the patient more than anybody and we are usually completely committed to their care. We know what is going on better than any health professional, and yet we are side-lined and ignored. There are so many complex issues with caring for children in your home with their children with mental health concerns. The parents with mental health concerns making decisions while acutely unwell for their children that also impact greatly on the family members care for the family unit to keep them together.

My main recommendations to the Royal Commission would be that:

1. **At the initial diagnosis and treatment of patients and or when they are first hospitalized, there should be a complete and thorough plan worked out for the discharge process and how it will take place**. **Including a whole section on who is the primary carers, ie parents, siblings/family members/friends involved in their care. Also are there children in the home that they will be returning to? What are the stressors that not only the patient will be returning to but they family will be experiencing. What referrals and supports can be put in place for them.** When a loved one goes into hospital for a mental health concern, there has been weeks and months of buildup of the patient getting more and more acutely unwell. There will have been so much confusion with the family members and particularly young children with what they would have seen and experienced their parent or sibling as the become acutely unwell. Which I have then seen lead to trauma for children in this confusing time. Planning needs to take into account where the patient will be living and with whom; security for the patient and the carers; the overall family environment and the effects on carers. This plan should be drawn up in collaboration with carers at the start of a patient's treatment process. If necessary, the health care providers at this time should write a

referral to the district nursing service to go and implement the medication to the patient. This would ensure that medications are properly administered and would take the strain off carers to do this.

2. **In families we often do not having just one person caring for someone with a mental health concern. We often have parents, siblings, partners and their are the children.** There needs to be recognition that there is more than one carer and that children at are connected to someone with a mental health concern need support especially when they have a parent with a mental health concern that goes in and out of psychosis. I have seen this very confusing for the children, that leads to behaviours of concern in the children themselves. Support is needed to help the children work through what they are feeling. Why is my parent not listening to me or caring for me at the moment, why is she unwell. Also putting supports in place so the family can stay together and if there are any neglect concerns putting measures in place so that the family unit is supported. If everyone got support with understanding the diagnosis, patient, carers and children / family and how to support the person in recovery then there would be better outcomes for patients and less family stress. There would not be the revolving door to the Adult Acute Mental Health Wards.

3. **There needs to be a local organization in almost every town which can act as a hub where carers can go to get access to health services and information**. These centres can also be places for support and education. For example, just assisting in writing documentation for NDIS would be a huge help. Writing referrals to services and other supports. Linking up with other organizations so that supports are in place. Case Management that is not determined on if someone has a NDIS plan or not for the carer to link in with.

4. **Carers should be able to support their loved ones with going directly to mental health specialists and to Mental Health Nurse Practitioners without having to first get a GP referral through a Mental Health Plan.** We need independent nurse practitioners who you can directly make an appointment with and come and visit in the home to provide support. Many people with mental health concerns do not believe they are unwell and will not make an appointment go to the doctor for a mental health plan then have to make an appointment to a psychiatrist or phycologist. This needs to be better streamlined. Going to a nurse who is connected with mental health specialists is less threatening than going to a doctor for first point of call. There is too many steps in the process when someone is in the first stage of Psychosis. At the moment you have to wait until they are so acutely unwell you can then get them to the emergency department in Ballarat to be seen and get care in the acute phase of being unwell, when they are a danger to self and or others. In this time children are very vulnerable, especially young ones. More supports should be in place when someone has been acutely unwell before for longer and have the capacity for families to be educated when they are entering the psychosis again. To prevent the longevity of neglect that can happen with young children and support the family to keep functioning and decrease the trauma the children can experience.

5. **Re-classify how assessments of patients' abilities or disabilities are made to include whether they need physical assistance. This is very important with not just Centrelink assessments for carers payment and carers allowance. It needs to include the emotional and psycosocial impact on carers. How often the carers are providing extendard periods of**

time calming a family member down, offering large amounts of social and emotional support. Are they able to take care of their personal hygiene for example. These assessments should take into account the burden on carers, carers financial circumstances and carer support payments that may be needed.

6. **There needs to be a thorough re-examination and assessment of NDIS as a mental health system.** It doesn't meet the needs to mental health patients or their carers. It is extremely difficult to navigate and access and it has created a population of mental health patients who are unable to make their way through the system themselves without assistance—and this assistance has had to come from carers. Someone who does not believe or will admit that they have a mental health concern means that carers to not have access to supports, even when they are living with the carer or carers or have extended periods of time supporting the loved one.

7. **More and better training for mental health care providers, other health care providers, police and emergency service workers in the symptoms and complex problems associated with acute mental health conditions including schizophrenia-related conditions.**

8. **Finally: bring carers into the centre of the mental health system, listen to them, include them in decision making and planning and use their knowledge, experience and skills to better the whole system.**

NO REFERRAL PROCESS for carer/consumer contacts – who does the ref, do they see people out of the ward? Needs to be a streamlined process, dif. Perspectives with peer workforce, additional support – its isolating going home.

Home help offered on discharged., can be overwhelming.